



Breaking Ground

A Self-Advocate Tells Her Story

By Laura Pfeiffer

My name is Laura Pfeiffer, and I am 19 years old. I am a recent graduate of Pearl-Cohn High School in Nashville.

I worked in the Child Care Center at the school. I also worked in the 2nd floor office during second period. I helped stuff envelopes, and I ran errands for the secretary and the assistant principal.

I took a computer keyboarding class and can type 30 words a minute. I also took math, English and art classes during my senior year.

I graduated from Pearl-Cohn this past May with a Special Education Diploma. I will spend the next two years in a community-based classroom learning different job skills.

After that, I hope to have a job that I enjoy and where I can earn money. I would like to move into my own place and not live with my parents any more. I would someday like to get a driver's license.

I have always gone to school with kids who do not have Down syndrome, and I learned so many things by being in the same classes with typical kids. For instance, I know all the capitals to all the states.

It has not been easy, but I work hard and do my best.

People are surprised at what I know and what I can do. I hope that other students like me get a chance to learn and be as successful as I am. I like music, dancing, swimming, gymnastics, and reading.

I am on the Board of Directors of the Arc of Davidson County as a self-advocate. I am registered to vote. In the last election I voted for Al Gore because he came and visited my school.

Please always remember that I am a person first who just happens to have Down syndrome. I want the people who make decisions about my life to listen to me and ask me what I think. I know what I like and what I don't like, and it is my life.

Thank you for giving me this time to tell you that I am a capable person who just needs people to give me a chance. ■



Laura Pfeiffer with her mom Mary

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My Trip to Washington D.C.

By Laura Pfleger

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I took a trip to Washington D.C. from February 9-13, 2002. I learned a lot about our national government. We stayed at the historic Mayflower hotel on Connecticut Avenue.

I saw different monuments like the Jefferson Memorial, Vietnam Veterans Memorial, Franklin Delano Roosevelt Memorial, Korean War Veterans Memorial, Lincoln Memorial and the Washington Monument. I liked the FDR Memorial a lot because he also had a disability. Often people with disabilities are treated unfairly and unkindly because of their disability. FDR tried to hide his disability because he thought people would think about him differently if they knew. When I visited the Lincoln Memorial, there were several wreaths of flowers below his statue because it was his birthday, February 12.

I was able to go to the Smithsonian Institution and visit the American History and Natural History Museums. I saw the Inaugural gowns of the president's wives. I was able to stand at a presidential podium.

I saw the Hope Diamond. I also saw a lot of dinosaur bones.

Washington was on "high alert," and security was very tight. There are concrete barriers around all the buildings and monuments. We were able to go to the Russell Senate Building, but we had to go through security like at the airport. That morning we met with one of the Senators from Tennessee, Bill Frist. I gave a short presentation to him about how well the Individuals with Disabilities Education Act (I.D.E.A.) worked for me in helping me get a good education. (See page one.)

Senator Frist listened very carefully to what I said. Since he is a Republican he laughed when I told him that I had voted for Al Gore in the last election because he came to my school. He said there was a good lesson in that for him. He gave us special passes to visit the Senate Chamber. Two of his interns went with us. If you look at the picture I have of the Capitol building, there is an American flag flying over the right, or Senate side of the building. That means that the Senate is in session. There is also a flag flown over the left, or the House of Representatives side when it is in session. If the light is on at night in the cupola, which is on the very top of the building, that means that the Senate or the House is in session. The Senate was in session while I was there, and members were voting on a bill. I saw Senator Hillary Clinton call the roll for the vote. While in the Capitol, I visited Statuary Hall and saw the statue of Andrew Jackson from Tennessee.

One of my favorite things to do in Washington D.C. is riding the Metro. The Metro is a train that travels underground like a subway. I learned how to pay for a ticket, how to use the ticket, and how to watch for the correct stop I wish they had something like the Metro in Nashville so I could get to places by myself.

I learned that our senators and representatives listen to what we have to say about the government and want to hear from us. I learned that I can make a difference. ■

(Front) Laura
with Senator Frist
(Back) U.S. Capitol.

Latter courtesy of Matt
??? and Andrea Cooper



Parents Look Back on Successes, Frustrations

By Jim Summerville

For a quarter of a century, a handful of supremely dedicated individuals have sought to affect educational policies so that Nashville's school system can live up to its claim to serve "all students," including those with disabilities.

"We are still outsiders," says Mary Pflieger, a key leader of these efforts over the years. "It's as if we are talking into a phone receiver not connected to a phone."

The story began when three mothers met over breakfast at Nashville's famed Pancake Pantry one morning in 1978. Each mom had a child with a disability in a special education school. At the time, Nashville had six such institutions, which at least gave children with disabilities the chance to set foot in a classroom. But these mothers were concerned about other issues.

The first was educational quality. There was no special education curriculum. Each teacher in each school acted independently from all the others.

The second issue was transportation. Some children were on buses two or more hours in the morning and again in the afternoon. None of the buses had radios, in the event of an emergency. None had aides to assist drivers with fragile students.

Over their pancakes, the trio decided to recruit other parents of students with disabilities to the cause. With Doria Panvini taking the lead, they formed the Special Education Action Committee, comprising two parents from each of the six schools and the principal from each one.

The ensuing years saw more children with disabilities entering into regular schools and classrooms. The committee grew to include teachers, teachers' aides, and representatives from disability agencies. By the early 1990s, there were subcommittees on transition, technical assistance, and other topics. "These panels were focused and effective," Ms. Pflieger remembers.

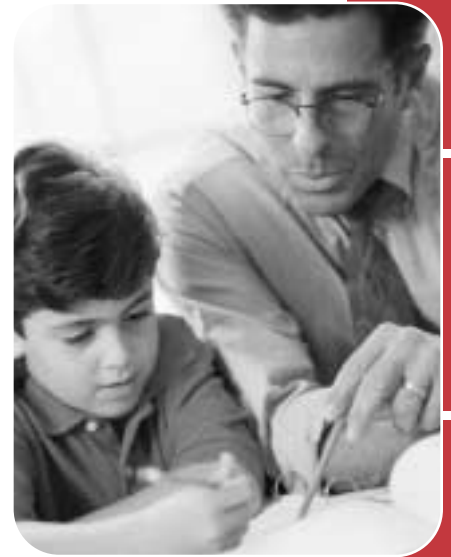
In the fall of 1994 the Action Committee had "a pretty ambitious list," she continues. "We wanted to help the Special Education Department of Metro schools to plan for transportation, for an extended school year, provide support for IEP goals, and more."

In less than two years, the group was moribund. "We sent out notice of the March, 1996 to a mailing list of 125 people. Not a single person attended." Ms. Pflieger says.

Involvement didn't seem worth the time to parents and others who led busy, crowded lives; the Action Committee was passive and reactive. It heard reports from the schools on disability issues, and parents who attended meetings expressed satisfaction or dissatisfaction. In no meaningful sense did it advise on policies or programs. When some problem arose concerning students with disabilities, the committee reacted with concern or frustration or even anger—but little concrete change resulted.

More fundamentally, even though staff members from Special Education Department attended meetings of the group, they seemed to have been ineffectual in getting the ear of School Board members or fellow bureaucrats up and down the line at the sprawling agency.

A new attempt. Feeling frustrated at the turn of events, Ms. Pflieger and holly lu conant rees considered how to revive the panel's work through some other means. "Since I chaired the education committee of the Arc of Davidson County, and since holly lu was a member, we decided to contact our school board representative, Betsy Walkup," Ms. Pflieger recalls.



continued on the next page

Ms. Walkup arranged for a meeting with Dr. Richard Benjamin, Metro director of schools, and the Special Education Department staff. As a result, Dr. Benjamin offered technical help from the Department of Education to create a new entity of citizens interested in the agenda of the late Action Committee. He also pledged departmental resources for training, helping with membership, energizing, and monitoring.

In July 1996, a task force to oversee the project began meeting, and a year later it had created EDAC, the Education and Disabilities Advisory Council.

This group had to be meaningful, Ms. rees told an audience in 1997. "Our input must

have the capacity to influence, so we can engage in collaborative decision making."

But the tortuous, year-long process to form EDAC did not augur well. It had been a struggle. "We wrangled. There was no common ground," says Ms. Pfeiffer.

Comity attended the announcement of EDAC, but conflict continued behind the smiles and handshakes. "The Director of Special Education wanted to limit the

parameters. She saw EDAC as a group of parents overstepping their bounds."

Far from "collaborative decision making," EDAC found itself on the margins when it came to special education programs, plans, and activities in Metro schools. When Metro undertook a restructuring of special education services, the effort was led by a group of principals, and only EDAC's holly lu conant rees was invited to represent students with disabilities and their families. She soon saw that EDAC, these consumers,

and school administrators understood many of the same words to mean entirely different things. The report of this "Special Education Improvement Task Force" received token implementation in one cluster of schools, then was soon forgotten.

Pressing on. In the summer of 1999, EDAC sought to institutionalize its relationship with the school system. Margaret Horsnell, the Director of Special Education, representing Metro Nashville public schools at EDAC, was given certain responsibilities in that role. These were specified in EDAC's "guidelines," an amalgam of a charter and bylaws.

According to the "guidelines," Ms. Horsnell would "access appropriate partners" among school bureaucrats. Further, she was expected to respond to recommendations from EDAC "in a timely manner," provide meeting space and refreshment, reimburse members for child care and transportation, and provide financial support for council activities, "as appropriate."

EDAC organized itself into committees. Perspective of parents, leaders, and students with disabilities had widened over time, and the group reflected this, with panels on playgrounds, preschool matters, recreation, and transition into adulthood. "What EDAC tried to do was get on committees that were making policy—and keep reminding people about our children," says Ms. Pfeiffer.

Ms. Pfeiffer and Ms. rees grant that EDAC's relationship with Ms. Horsnell led to some gains. "She helped promote EDAC's guidelines. It was really a matter of taking several years to build up trust with each other. The last few years we have had a productive working relationship with her." "She sees that EDAC can be a source of support, rather than an enemy," says Ms. Pfeiffer.

"Because we have contacts with families, we can provide a rationale for changes in programming. The concept of a family advisory council [to the Special Education Department] was a new one, and to this day Metro Nashville is one of the few school districts that has one."



“Where the Public Schools Strategic Plan speaks of ‘all children’, does the school board really mean that?”

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Otherwise she and Ms. rees are less sanguine. “Margaret Horsnell agreed with much of what we said, but was powerless to change much. The struggle is more about entrenched attitudes and policies that still prevail today.”

The Metro Nashville Public Schools Strategic Plan, 2002-2006 was adopted by the Board of Education with “no involvement by EDAC or the disability advocacy community,” says Mary Pfeiger. “Where the document speaks of ‘all children,’ does the school board really mean that?” As this issue of *Breaking Ground* went to press, EDAC was writing a response to the plan. EDAC leaders are worried that a criterion like “increasing test scores” across the system will mute the ideal of achievement for each student. For example, if there’s instituted a standard “gateway” examination requiring certain literacy benchmarks—what about students with disabilities who can’t read?

Despite the continual move toward greater understanding and trust, the last year has “been a strange one,” allows Ms. Pfeiger. “We have a new director of schools who has basically ignored us.” EDAC, she says, sees the need for the special education director to have authority to intervene with principals, since they “are the key people when implementing IDEA.

“If a principal of a school does not take ownership of all students zoned to that school but rather sees students with disabilities as ‘belonging’ to special education, then we have a big problem.”

It has been 24 years since Doria Panvini brought together a few mothers concerned about the education of their children. Today the concerns linger.

“Is there anyone on the school board who knows anything about children with disabilities?” asks Mary Pfeiger. “Where is their voice?” ■

Tennessee Disability Information and Referral Office (TDIR)

For individuals with disabilities, family members, and agencies

Information about disability services and supports

Toll-free hot line

Statewide 800 640-INFO (4636)

TDD 800 273-9595

Nashville 615 322-8529

2001-02 East, Middle, and West Tennessee Services & Supports Directories available

\$40 per directory or \$80 full set
Call or place order by Internet
<http://kc.vanderbilt.edu/devents/order.html>

Tennessee Family Pathfinder www.familypathfinder.org

A one-stop Internet gateway to services and resources in Tennessee and to national resources, including Spanish sites

Link to “Search for Services” to search the TDIR database of 1400 agencies by county and service type

Projects of the Tennessee Council on Developmental Disabilities and the John F. Kennedy Center, Vanderbilt University

Tennessee Disability Training Network www.disabilitytrainingtn.org

A searchable calendar of training events and other Tennessee and national disability-related events. ■

Microenterprises Gain Momentum in Tennessee

By Jim Summerville

According to the federal government's Small Business Administration, enterprises employing fewer than ten workers are the backbone of the U.S. economy.

Owning and managing a small business is becoming an increasingly attractive option for many people with disabilities. Self-employment offers a high degree of flexibility and appeals to people who are used to finding new ways to do routine tasks. People with disabilities are used to being persistent, which translates well into the world of small business. Finally, people with disabilities are accustomed to making the most of two precious resources, time and money, another essential business skill.

What is a microenterprise? A microenterprise is defined as a business with five or fewer employees that requires startup capital of \$35,000 or less. Most microenterprises create employment for the owner and, often, family members. Some grow into larger operations and hire others to help.

Microentrepreneurs pursue endeavors that fit their interests and abilities. Common types of businesses are repair services, cleaning services, specialty foods, jewelry, arts and crafts, gifts, clothing, computer technology, child care, and environmental products or services.

Getting help. If you're currently operating a microenterprise—or might be interested in starting one—you can find help from a microenterprise development program. According to the Association for Enterprise Opportunity (www.microenterpriseworks.org), some 700 of these development programs operate across the country. Thirteen of these are found in Tennessee, ranging from Memphis's Catholic Charities to Sneedville's Jubilee Project.

Microenterprise development programs help entrepreneurs to develop the skills they need to

plan, market, and manage their businesses. One of the outcomes of this training is a formal business plan, which will identify the market for the business and how to reach it in profitable ways. For example, the business developer might learn about participating in trade shows, developing catalogs of products, and advertising the business on the Internet. The training can also address issues like family budgeting, control of personal finances, and appropriate business behavior.

Microenterprise development programs also assist business builders to get started by obtaining access to financing. Some programs operate in-house lending programs. Others have developed links to collaborating banks, public loan funds, or other sources.

Of key importance is the ongoing assistance that the microenterprise development program makes available to the new business owner. After the start-up phase, participants can obtain services that help them overcome obstacles to staying in business or growing the business.

Funding, training, and other assistance.

Some of the first microenterprise programs were engendered in Tennessee beginning about 1997, with the Memphis Center for Independent Living (MCIL) providing the lending, training, and technical assistance. MCIL brought together some two dozen entrepreneurs, formed into the Gainful Opportunity Advocacy Leadership Society (GOALS) GOALS created its own loan fund, and within a year, it had made about \$10,000 in loans.



“Freedom, flexibility, and independence make small business ownership attractive to people with disabilities”

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Also in Memphis, a joint program by an historically black college and a local financial institution supports microenterprise. The AMSOUTH Bank Center for Entrepreneurship (CFE) and LeMoyne-Owen College's Community Development Corporation (CDC) assist existing and prospective entrepreneurs with financing through three programs of small loans. Once the loan is made and the business is up and running, Center staff provide management and technical assistance. People with disabilities have often lacked access to capital, training, and ongoing help that a business requires—and which CFE/CDC offers in the Bluff City.

Throughout its sprawling system, the Tennessee Valley Authority supports small business incubation. It presently has 20 facilities where microentrepreneurs can share space, equipment, and services. The Business Incubator Tenant Loan Fund is available to help tenants meet short-term cash flow needs and operating capital.

The U.S. Small Business Administration has established several programs in Tennessee where non-bank lenders make loans for microenterprises. The newest, Woodbine Community Organization Small Business Program in Nashville, can now lend up to \$35,000.

It's working. These and other public and private lenders to microenterprises in Tennessee are playing good odds. That's because microenterprises backed with training and technical assistance have a success rate of 80%, according to Michele Flynn, executive director of The Tennessee Network for Community Economic Development (TNCED). TNCED, a statewide association of community development groups, advocates with state lawmakers for legislation friendly to microenterprise. It worked with local governments to establish microenterprise

programs, using federally-funded community development block grants. Finally, TNCED encourages and facilitates exchange of information among microenterprise development programs and seeks to strengthen their capacity.

Ms Flynn notes that about 25% of people involved in microenterprises in Tennessee have a disability. “Some do so because they are entrepreneurial by inclination. Others look to microenterprise as a way of overcoming barriers to other kinds of employment.” She cites two reasons why self-employment and small business ownership are attractive to people with disabilities:

- freedom, flexibility, and independence because you work for yourself
- freedom from access-related barriers in transportation and work environments

She adds that TNCED has been encouraging the state's Division of Rehabilitation Services to help make its programs and services “more user friendly” to microenterprise businesses and clients who are undertaking them.

According to the Office of Disability Employment Policy, U.S. Department of Labor, a small business owner with a disability can still receive income support, such as Social Security or Supplemental Security Income disability payments by staying within the income and asset requirements of those programs. ■

Editor's note: In a future issue of *Breaking Ground*, we will report on several microenterprise success stories by people with disabilities.

Jim Summerville
is editor of
Breaking Ground.

Presenting the 3rd Annual Tennessee Youth Leadership Forum Class

By Ned Andrew Solomon

I am so very proud to announce that the 2002 Youth Leadership Forum class has been selected. By the time you read this, 20 outstanding high school student delegates with disabilities from across the State of Tennessee will have met on Vanderbilt campus for four days of non-stop activities.

Highlights included presentations by local and national speakers in the disability field, small and large group discussions on leadership and a variety of disability topics, a trip downtown to tour the Capitol, meet with a State Representative, and eat lunch with adult mentors from the community, a photography workshop, a talent show, and lots of mingling and networking with new friends.

It is quite an impressive group. We have students who have made great strides to become involved in their schools, churches, and their communities at large. Many have been involved with service projects that shatter the misconception that individuals with disabilities always need support and cannot be in the role of helping others.

They have served as reporters, sport team managers, student council representatives, public speakers, Girl and Boy Scouts, tutors, hospital volunteers, fundraisers, marching band members, youth group leaders, pageant winners—the list goes on and on and on. They have faced and overcome personal challenges and become role models and trail-blazers for younger students with disabilities coming up through the system.

And after reading some beautiful letters of recommendation, it is clear that these youth have touched many adult lives along the way.

So without further ado, here they are:

Mary Grace Williams



Brenda Adams—Nashville
Scott Bailey—Oak Ridge
Jessica Bean—Knoxville
Kelley Brooks—Chattanooga
Catya Campbell—Chattanooga

Amanda Crowe—Johnson City
Beth Davis—Oak Ridge
Jackson “Stoney” Enix—Powell
Justin Grandberry—Somerville
Beth Hopkins—Madison
Spencer Jackson—Tulahoma
Daniel Moody—Oakland
Cody Murphy—Bethel Springs
Lindsey Painter—Manchester
Tyrice Porter—Jackson
Amanda Reedy—Germantown
Jessica Rhea—Blountville
Maya Spencer—Louisville
Nicholas Trail—Manchester
Mary Grace Williams—Cordova

It has become a tradition at *Breaking Ground* to showcase a handful of the selected students, by presenting excerpts from the essays submitted with their applications. So meet the next generation of teachers, politicians, actors, social workers, disability-rights advocates, community leaders and all-around movers and shakers! I'm certain you will be hearing more about them in the future. ■



Scott Bailey:

When I was eleven years old, I attended a summer science camp sponsored by the Oak Ridge National Laboratory (ORNL). I was the only deaf one in the group, but that was not a problem for me.

I was really surprised when I received an invitation from ORNL to speak in support of the science camp program at a luncheon in the Executive Dining Room. I was told that in the audience would be Dr. Martha Krebs, Director of Science for the U.S. Department of Energy.

I was hesitant to accept this invitation, but my mother encouraged me to go. She went with me as my interpreter. There were many government officials present, both local and national, but I presented my speech and answered their questions without any problem. Despite being nervous, I learned about the politics of federally funded programs and how people benefit from these programs. ■

Justin Grandberry:

The experiences that I have had as a person with a disability started at home. There I am not treated like I have a disability. I have chores to do at home like any other person. They are not always easy for me, but with love and patience I've learned I can do them.

My plan following high school graduation is to attend a two-year technical college and get an information technology degree. I like working with computers because I can do a lot of things on a computer. I would also like to be a businessman. I feel like I would be a good sales person because I like dealing with people.

When I graduate from technical college, I plan to get a job in the information technology department of a Fortune 500 company and earn a good salary. I plan to get my own apartment and a car after I finish college. I plan to make my mother and me very proud. ■

Tyrice Porter:

Attending the forum this year would be a great achievement for me. I want the growth that it would allow me as a person. I have not been away from my family alone before, and this would be a great opportunity to prove to myself and my family that I am capable of taking care of myself. I have had a vision problem since birth, but I have worked hard to overcome my limitations and to work toward a larger goal. I am very interested in the laws that affect people with disabilities. I have experienced what can happen if you

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are not aware of your rights. I want to learn all that I can to help myself and others, and I am willing to work for the community. I have had to learn with great effort what many people take for granted. I think I could represent people with disabilities very effectively because as my mother always says, "Experience is the best teacher." I know that she is right. It's a challenge to live normally but with motivation and encouragement it can happen. ■

Nicholas (Nick) Trail:

I appreciate the opportunity to apply to be part of the forum on disability issues. I believe that a person is limited only when he or she limits themselves. I developed cerebral palsy due to a premature birth. Ever since I can remember,

my parents and other family members have taught me never to limit myself. There is always a way to be part of or to have a voice in subjects that interest us. That is what makes life worth living. I realize that not everyone who has a disability has had the loving support that I have. However, they are not any less deserving to be able to reach their goals. If I had the opportunity I would like to show and tell others

that we can all accomplish great things in life, whether or not we have a disability. People make things happen with determination and persistence. With those things, we can all accomplish our dreams. ■



Maya Spencer:

When I was 12 years old, I really wanted to earn a special award given by my church called the "Gospel in Action" award. One of the requirements was to memorize and recite specific passages of Scripture. Because of my learning disability, I have a very hard time memorizing things. I tried and tried, but every time I stood up to recite, I'd get nervous and self-conscious, which caused me to get confused and make mistakes. After many months of working at it, I was ready to give up. Then I talked with my mom. She spoke with one of the ladies at the church about the problem, and together we came up with the idea of learning the passages one at a time and then reciting them in front of a video camera. With a little outside help, I was able to achieve a goal that was really important to me. I also learned a valuable lesson about approaching challenges with a creative and positive attitude.

My immediate goals are to get a date for the prom and to graduate from high school, hopefully ahead of schedule. After high school, I plan to attend Pellissippi State Community College. I'm not sure what I want to major in, but I think I would eventually like to work with an organization like Habitat for Humanity. I also want to serve a two-year mission for my church when I turn 21. I plan to marry and have a family. I hope to maintain a close relationship with my family, to be active in my community and my church, and to advocate for my brother and other people with disabilities whenever and wherever I can. ■



Brenda Adams:

I would like to tell you of a decision I made that changed my life. I went to the Tennessee School for the Blind (TSB), a state school for people with visual impairments for eight years, then transferred to a public high school. At TSB I never felt any different from anybody else. All the supplies we needed were always provided. You did not have to ask for special supplies just to do homework.

The older I got I started realizing I was missing out on a lot of fun stuff that other kids my age were doing at their schools. I asked my mama about going to public high school. We went to visit Glenclyff High School at the end of my eighth-grade year. It was so big—there were so many kids, a lot more than at TSB. I started attending the ninth grade. I really had to start being my own advocate. I had to tell the teachers what I needed as far as lighting and materials. If I didn't tell them they would not know. I think the teachers have learned a lot from me these past four years. I think Glenclyff will be more prepared for another student with visual impairments who might attend in the future. ■

Lindsey Painter:

Because of my disability, I have been given the chance to play many different sports. It makes me feel like I belong to a group, and I don't have to worry about people making fun of me because we can all relate to each other. Through the sports program I have also been able to get involved in wheelcheerleading. I always wanted to be a cheerleader, and now we have a very inspirational woman, Bethany Hoppe, who has formed the

first wheelcheer-leading troupe anywhere. This has been a very exciting opportunity for me.

My other awesome experience has been the honor of being crowned Junior Miss Wheelchair Tennessee, 2001. It opened the doors of communication between me and my peers, and they now know I'm a person with feelings just like they are. Just because I have a disability doesn't make me any different. Because of newspaper articles and public appearances during my reign, I hope I have raised awareness of people with disabilities so that others might see them in a positive light, rather than feeling sorry for them like they can't be successful. ■

Kelley Brooks:

In one second my life was changed forever. On February 2, 2001, due to a car wreck, I became a paraplegic, dependent on a wheelchair, and unable to do many things that were once very important to me. Yet, as the days went by and my body began to heal, I realized that no matter how miserable the situation may be, I must continue to live life to the fullest in a different way. While in the hospital I began to think of new ways to keep myself active and busy. I decided to run for junior class president since I had been class president in previous years. When returning to school three months after the wreck, after going through extensive physical rehabilitation, I decided to pick up my life where I had left off.

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I joined numerous clubs and kept involved in dance classes, where I had spent many hours a week before the accident. Although it was different than I had been accustomed to, it served as a means to keep me involved in things I had loved to do.

Although I have only been in a wheelchair for a year, I have been able to show more than 1,800 high school students that being in a wheelchair does not mean that one cannot live life like any other person. It was surprising for many people to see me drive to school, unload my wheelchair by myself, be involved in many school clubs, volunteer, go to a job, and have

a social life. I hope that every day I can break the stereotypical barriers that are associated with people with disabilities. ■

If you would like more information about YLF, or would like a delegate or volunteer staff application for the 2002 class, please contact:

Ned Andrew Solomon

**Director, Partners in Policymaking TM
Tennessee Council on Developmental
Disabilities**

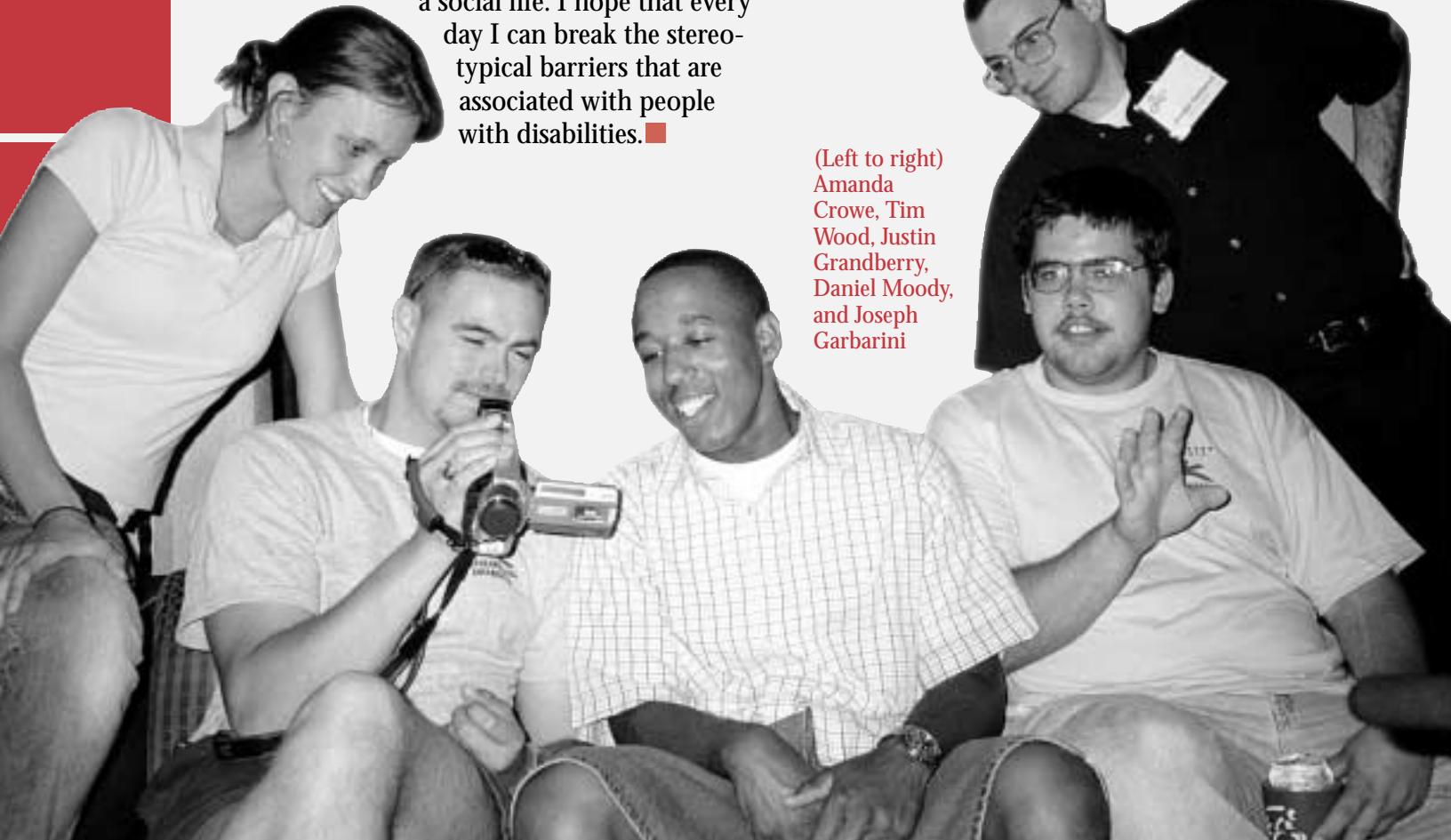
Andrew Jackson Building

13th Floor, Suite 1310

Nashville, 37243-0228

Phone: (615) 532-6556

ned.solomon@state.TN.us



(Left to right)
Amanda
Crowe, Tim
Wood, Justin
Grandberry,
Daniel Moody,
and Joseph
Garbarini



Giving Joyful Care

By Del Ray and Madeline Nichols

In December 2001, we enrolled in microboard training in Nashville, having heard about the program from a friend. Our initial interest quickly turned to enthusiasm after listening to Jackie Golden, executive director of the Inclusion Research Institute, Washington, D.C., and Brian Dion, director of residential services for the State of Tennessee. We decided to organize a microboard as soon as possible for Joy Beth, our daughter who suffered severe brain damage from herpetic encephalitis in 1982 when she was nine years old. Her current residential provider was experiencing a huge turnover rate, presenting major staffing problems for Joy Beth.

Our first step was to inform our family and friends that we would be forming a microboard, a nonprofit company controlled by a volunteer board of directors, to care for Joy Beth. Next we scheduled a PATH for Joy Beth. PATH stands for Planning Alternative Tomorrows with Hope.

There was the inevitable paperwork. Jackie Golden had provided us a sample charter and bylaws, which we adapted to fit our specific situation. Next, we had to complete a provider application, required by the State of those who provide long-term residential supports.



By February we were ready to submit our application for approval, following a review by Brian Dion.

While in Nashville, we had our company chartered under the name Joyful Care, Inc. Later, a dear friend provided the perfect logo! (See opposite page.)

Ruthie Beckwith of the Tennessee Microboard Association attended our first board meeting and began to do the much-needed training we would need to provide Joy Beth a circle of support. That training continued through the spring at the regional office of the Division of Mental Retardation Services in order to satisfy state requirements for operating a company like ours.

On April 8, our application was approved. Now plans began in earnest to switch Joy Beth's care from her current residential provider to Joyful Care, Inc. We set up employee payroll policies and benefits and began taking applications for the different shifts.

May 26 was the Joyful Care, Inc.'s first operating day. Joy Beth continues to live alone in the home she has rented for the past six years with the help of supports hired by Joyful Care.

We, her family and friends who know and love her best, are now in control of her care,



(Below and facing page) Friends and family surround and support Joy Beth. Some have joined to form her microboard.



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thanks to the microboard. Her siblings, who have felt disconnected from that care, can now participate. Formerly, the independent support provider meetings took place during the work day, hindering Joy's siblings from attending. Joyful Care board meetings are held in the evenings at Joy Beth's home. Joyful Care, Inc.'s Board of Directors and circle of

support include Joy Beth herself, her parents, siblings and their spouses, a former special education teacher, a former pastor, and several other friends.

Joy Beth's family wants to have the responsibility for her care, and the microboard has given us a way to do that. Joy Beth also has a more stable, safe, and secure environment. ■



Tim's Microboard

By Betty Henderson

It was 1999, and Tim had been in his own home in the community since his discharge from Arlington Developmental Center on December 14, 1996. He was with his third community provider agency. This one was as unprepared and unresponsive to his needs as the others had been.

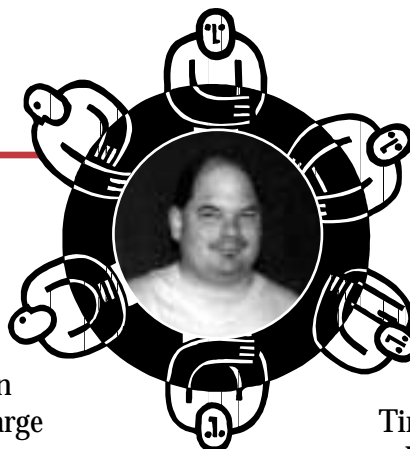
They could talk the talk

"Supported Living! Sure, we do supported living! We were one of the first providers in the country to do person-centered planning and supported living!"

But walking the walk, that was a different story: When the contracts were all signed and they were staffing Tim's home, they would say to their staff, "Tim's mother, Mrs. Henderson, is picky and she visits too often and expects too much and Tim gets upset when his Mom and Dad come, so we really would prefer that they not visit so often." "It really does not matter what Tim and his family want, we are your employers and you will do what we say!" "You do not work for the Henderson's, you work for us."

Then there was the turnover. Tim had new staff to get used to almost every week. Most of this staff had been fired from another agency and were being recycled. No one asked too many questions about why they had left the last agency; they already had their core training, so hiring them was the cheapest way to go.

Tim had just gone through a year of self-abusive behaviors because the community provider agency's staff refilled his medication with a generic instead of the brand name. (This happened in spite of the fact that it was plainly written in Tim's transfer packet to make sure that it did not happen!) This started a chain reaction of negativity that escalated to the point of making Tim's life unbearable. We were told by our "broker" that it really didn't matter if the services and supports that were provided were of



poor quality, the provider got paid if they had warm bodies that showed up for each shift!

This prompted me,

Tim's mom, to start

researching to find a better way. I

visited web sites and read everything I could find on supported living, direct funding, microboards, gentle teaching, and so forth. I e-mailed everyone to ask questions and talked with Jackie Golden, executive director of Inclusion Research Institute of Washington, D.C., who had started a microboard for her son Joshua. Then I heard that the Council on Developmental Disabilities was awarding a grant to get microboards started in Tennessee! That was exciting news!

A vital issue

We knew that Tim would not survive another year with an agency that was not receptive to his needs. And, we knew that we could not survive another year of staff people who burned holes in his sofa and carpet while he slept. We went to the regional director and told him that we knew of a family that was looking after their son's home and training and hiring their own staff, and we wanted the same sort of contract until we could get our application for the microboard finished. This request was granted, and we have hired and trained the staff that is in Tim's home.

This past year has been a preview of what life for Tim will be when we get his microboard functioning. Tim's staff has a wonderful sense of responsibility about him. They work very well together and cooperate with one another. If something happens and a staff person cannot come in, our home manager, Stephanie Davis, can be there in a very short time and if she cannot be there, another one of the staff can. The staff respect Tim, and celebrate his differences without trying to change him, and they respect his family connections enough to help him remember and shop or make cards for birthdays, anniversaries, graduations and births. They have found so many ways to include him in the fabric

of their personal lives as well. He is included in birthday parties for children and grandchildren, ballgames and community outings, and more. God has blessed us with caring, generous, loving people to help us care for our child.

About Tim's microboard

Tim's microboard is small, a circle set up to support one person with a disability. This board consists of at least three people and not more than nine. Tim's board has a President, Vice President, Secretary and Treasurer. We have filled out an application and when TennCare and the Division of Mental Retardation Services approve it, Tim's Place, Inc. will be a community provider agency. This agency will be able to bill the State of Tennessee just like any other agency in the State. This will enable us to compensate our employees according to their commitment to support Tim in a meaningful life deeply embedded in his community and family. It will enable Tim to have the authority and freedom to use his public funds to hire supports that are receptive to him and his interests and his values. He will have the power to decide who will be in his home. The power will shift to the place it should have been all along, to Tim!

We hope to have Tim's Place, Inc., up and running sometime this summer, and we have all sorts of plans to make life interesting and productive for Tim and his staff.

Tim's Place, Inc. has had a PATH (Planning Alternative Tomorrows with Hope) a futures planning event, facilitated by Ruthie-Marie Beckwith, Steve (Jake) Jacobs, and Leanne Boyce. This was also the time that we invited our prospective members and citizens of our community, family members, and co-workers to come, join in, listen and decide if they wanted to be a part of this innovative way of life for Tim. We have now participated in three board meetings where we have learned the responsibilities and duties that are required of a microboard. We have elected officers (with Tim being the newly elected President). We have legally incorporated and sent off to the Internal Revenue Service for an employer identification number. We are in the

process of opening a bank account for Tim's Place, Inc., ordering business checks, and hiring an accountant who will be trained on how to bill the State of Tennessee. And we are making contacts for Tim each time we meet or tell someone our plans. This will ensure that others in our community, who may need services and supports in the future, will be made aware of the Microboard option.

Tony Records and Associates, Inc., with Ruthie-Marie Beckwith of Murfreesboro, Tennessee, as project manager, was awarded the grant to get microboards and the Tennessee Microboard Association up and running in the State of Tennessee. She hit the deck running with the idea, and it has been gangbusters in the almost 10 months since inception. She has had such a positive reception that it has been almost overwhelming! There are now 12 microboards in different stages of organization.

Tim's family and friends are excited about his microboard. Our expectations are that this will be a way to promote inclusion in the community for individuals with disabilities in keeping with the principles of self-determination; freedom to live a meaningful life in the community of choice; authority over the dollars needed for quality supports and services; support from caring individuals to organize resources in ways that are life enhancing; meaningful, responsibility for the wise use of public dollars; and the importance of the leadership that self-advocates must hold in a newly-designed system! ■



Dancing is a favorite recreation of Tim's.

For more information, contact

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Lorre Leon Mendelson,
Project manager for TP&A

Council on Developmental Disabilities Funds Voter Projects

The Tennessee Council on Developmental Disabilities is awarding two grants to address voter education and voter registration in Tennessee as part of its Voter Project Initiative. (For more information, see article in *Breaking Ground* #6.) Both projects will be non-partisan and explicitly detached from any political party or candidate.

Tennessee Protection & Advocacy, Inc. (TP&A) began the Tennessee Voter Empowerment Project of People with Disabilities on July 1, 2002. Their vision is that people with disabilities in Tennessee are fully included as citizens in their communities and experience barrier-free access as they exercise their constitutional right to vote.

The desired outcomes for the project are:

1. Persons with disabilities understand their voting rights and are empowered to vote.
2. Persons with disabilities have access to voting activities.
3. Persons with disabilities are advocates for themselves and for others with disabilities.
4. Disability and non-disability organizations are knowledgeable about the needs, issues, and voting rights of persons with disabilities.
5. Election officials and policymakers are knowledgeable about the voting rights and issues of persons with disabilities.
6. Disability and non-disability advocacy organizations actively collaborate to improve voting access for persons with disabilities.

TP&A proposes to use a combination of educational forums, training, conferences, public service announcements, and video and print material to educate people about and advocate for voting issues. It will participate in the development of statewide and regional voting councils to oversee and monitor progress toward the desired outcomes. Finally, it will provide consul-

tation to agencies and organizations to help them meet the voting needs and address the voting rights of persons with disabilities.

TP&A believes that education of potential voters is key to the success of this project. The organization will begin its effort by assisting leaders of disability and non-disability organizations in the education and empowerment of their memberships. TP&A will also provide training for individual members to reach into their personal communities, to educate their friends, family members, and colleagues. The educational efforts of the TP&A project will reach out to people with disabilities; election officials, staff, and local poll workers; disability organizations; and non-disability community organizations and their members.

The project manager for TP&A is Lorre Leon Mendelson. Lorre is a consumer advocate with more than thirteen years experience working in the disability community in areas of access and accommodations, job development and employment services, counseling, education, instruction, and consultation. Lorre received intensive voter empowerment training from Ken Steele (New York Mental Health Association) and the National Mental Health Association Voter Empowerment Project (January 2000) and implemented this program in northern California for people with mental illness, other disabilities, and additional groups that are disenfranchised. In 2000, Lorre participated with the Registrar of Voters in Santa Clara County, California, consulting as a trainer on disability issues and access to voting activities as well as on a volunteer basis for Voter Registration Week in California. Lorre is currently preparing a voter empowerment presentation for the Annual National Association of Protection and Advocacy Systems Conference in June 2002.

The Tennessee Disability Coalition (TDC) began a Voter Registration Project on July 1, 2002.

Working with Partners and collaborators within the disability community and partners and collaborators within the civil rights, social justice, minority, and activist communities, the TDC will establish new partnerships with organizations that serve people with disabilities in a variety of ways. Initial voter identification and registration will take place through these partnerships.

The outcomes of the project will include:

- Increased compliance with National Voter Registration Act (NVRA) among state agencies and others
- Increased numbers of people with disabilities and their supporters who are registered to vote
- Identification of "disability" voters (people with disabilities and their supporters) who may vote
- A voter database that can be used to provide voter education and to get out the vote

To achieve these outcomes, TDC will use extensive outreach and communication within the disability and social justice communities. Key components of the project will be direct contact, information dissemination, and relationship building. Use of effective information systems and data collection is also critical.

TDC proposes to

1. Upgrade its current Web site to include voter registration tools and data collection capabilities, in addition to the provision of other voter information
2. Develop and expand data systems and tools that will identify voters and potential voters with disabilities

3. Use existing agency membership and consumer lists for direct mail survey and solicitation for participation in the voter database. Include registered respondents in the voter database. Assist unregistered respondents to register
4. Identify other lists from which to draw disability voters. Use direct mail or other personal contact to solicit participation and inclusion in the voter database
5. Work with the Secretary of State to solicit the support and participation of disability agencies as "other designated registration agencies" under the NVRA
6. Work with mandatory state registration agencies to increase NVRA compliance and to partner for release of information to the voter database
7. Identify and enlist a minimum of 27 disability organizations and agencies as partners for the registration campaign
8. Support the development of registration campaigns within targeted groups
9. Directly register voters ■

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About the Council:

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

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